Supporting caregivers of stroke patients

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CHAPTER 3

Risk factors for Burn-Out in Caregivers of Stroke Patients, and Possibilities for Intervention

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Abstract

Objective: In this article we wanted to identify which caregivers of stroke patients living at home experience the highest levels of strain and are at risk for burnout, and to investigate how support for caregivers of stroke patients could best be organized, and when this support should be offered.
Subjects: Caregivers of stroke patients were recruited in four regions of the Netherlands. A total of 212 caregivers were interviewed. Multiple stepwise regression analysis was performed to determine the effects of patient and caregiver characteristics, resources, coping strategies and duration of *the* caregiver role on caregiver strain, mental well-being and vitality. The majority of the caregivers were female spouses. Their mean age was 64 years, and their socio-economic status middle class. Stroke had occurred about 3.5 years ago on average.
Methods: The following main outcome measures were used: the Caregiver Strain Index, and two scales of the Short Form 36 to measure caregivers' mental wellbeing and vitality.
Results: Severe cognitive, behavioral and emotional changes in the patient constitute the main risk factors for caregiver burnout. Women, younger caregivers and caregivers in poor physical health were also identified as risk groups. Caregivers with high perceived self efficacy, satisfied with social support, and frequently using the coping strategy confronting, experience less strain, higher mental well-being, and greater vitality. Duration of the caregiver role does not influence caregivers' strain, mental wellbeing, or vitality.
Conclusion: Women, younger caregivers, caregivers in poor physical health, and caregivers of patients with severe changes are at risk for burnout. Support programs should focus on self-efficacy, social support, and the coping strategy confronting. No specific moment could be identified at which support programs should be offered.

3.1 Introduction

Most stroke survivors return to their own home after a hospital stay and a rehabilitation program. From that moment on it is the caregiver who has to look after the patient. Caregivers of stroke patients often have to cope with patients' physical and cognitive impairments, communication and behavioral changes, and emotional problems. Some caregivers do well in this situation, others experience stress and depression. In the long term some are unable to continue looking after the patient.[1, 2]

Earlier studies on caregivers of patients with different diseases (dementia, Alzheimer's disease) demonstrated that both patient and caregiver characteristics play an important role in the consequences experienced by caregivers.[3, 4] Several studies reported that the severity of the consequences of a disease increases the level of caregiver stress.[5-7] Other studies, however, did not support this finding.[8-10] Some found that strain and well-being can also be affected by caregiver characteristics, such as age, gender, and socio-economic status.[4, 7]

The stress-coping theory of Lazarus and Folkman states that people under stress first appraise the severity of the consequences of a stressor (primary assessment) and, secondly, the available resources and possible coping strategies (secondary assessment). Primary and secondary assessment influence each other and determine the amount of stress experienced. Finally, the coping process starts with a person adopting a coping strategy (active or passive). The effectiveness of a chosen coping strategy and assessment influence a person's social functioning, mental well-being, and physical health.[11]

Lazarus and Folkman state that resources like information, assertiveness, social support, health, material resources et cetera play an important role in assessment and coping processes. Indirectly these variables influence a person's well-being. Several caregiver studies reported a positive influence of such resources on caregiver strain[2 12-14], whereas others did not support this finding[15].

It is unclear whether active or passive coping strategies are more effective in reducing stress. Whereas some studies have found active coping strategies to be more successful, in general, problem-solving strategies appear to be effective in situations where change is a real possibility.[16-19] If this is not the case, more passive strategies appear to be more useful.[20-22]

Two theories focus on the influence of the duration of the caregiver role on caregiver stress. The cumulative stress theory states that caregivers' stress increases over time, whereas the adaptation theory states that over time caregivers learn to adapt to the situation.[23] By knowing the effects of duration, it becomes possible to establish when caregivers are most in need of support, that is, at an early or at a later stage of their caregiver role.

To identify caregivers at risk for burnout, and to find indications regarding the organisation of an intervention for caregivers of stroke patients, we formulated the following research questions: are caregivers' strain, mental well-being and vitality influenced by:

1. patient characteristics (gender, age, severity of the consequences of stroke)?
2. caregiver characteristics (gender, age, physical health, socio-economic status)?
3. resource variables (knowledge, assertiveness, income, social support)?
4. the use of active coping strategies (confronting, seeking social support)?
5. duration of the caregiver role?
6. which of these variables are most dominant in influencing caregivers' strain, mental well-being and vitality?

3.2 Methods

3.2.1 Sample and procedure

Caregivers of stroke patients were recruited in four regions of the Netherlands. From February 1995 till July 1996 caregivers were recruited via general practitioners, hospitals, home care organizations, rehabilitation clinics, the media, and an organization for caregivers and stroke patients. Professionals were approached and asked to inform caregivers and patients about the research project. In a special leaflet for caregivers and patients the research project was described. Caregivers and patients who wanted to participate had to mail an enrolment form to the researchers.
Caregivers were included if: the first stroke of the patient occurred between July 1992 and July 1996, the patient was aged 45 years or older at the time of the first stroke, the patient was living at home and the caregiver was the patient's main caregiver.
Two interviewers conducted separate interviews with the caregiver and the patient in their own home. Before the interview caregivers and patients had to fill out an informed consent form. The medical ethics committee of Groningen University Hospital approved the study.
A total of 257 caregivers who met these criteria were included during the 17-month inclusion period. Twenty-three caregivers dropped out before the interview, the main reason being the caregiver's poor health. During the interview-period another 22 caregivers dropped out mainly because of death of the patient.

3.2.2 Assessments

In the interview with the patient the severity of stroke was measured with the short version of the Sickness Impact Profile (SIP-68), which consists of 68 items.[24] The caregiver was asked about the psychological consequences of stroke using an instrument developed by Schure, focusing on the cognitive (six items), emotional (six items), and behavioral consequences (five items) of stroke (explained variance 53.9%).[2]
The Occupational Prestige Scale of Sixma and Ultee was used to measure caregivers' socio-economic status.[25] The scale physical functioning of the Short Form-36 (10 items, alpha=.92) was used to measure caregivers' physical health.[26]
The researchers developed an instrument of 30 items, asking subjects about their confidence in own knowledge. Caregivers were asked to rate on a five-point scale how much they thought they knew about a specific theme.
We assessed the use of active coping strategies, using a short version of the Utrecht Coping List.[27] The total list contains four factors explaining 53.9% of variance. Only the factors representing the active coping strategies confronting (five items) and seeking social support (five items) were used. For the measurement of assertiveness a questionnaire was developed (15 items).
The amount of social support was measured with an adjusted version of the Social Support List-interaction (five items), and satisfaction with social support was measured with an adjusted version of the Social Support List-Discrepancy (five items).[28]
The three outcome measures of interest were strain, mental well-being and vitality. Strain was measured with the Caregiver Strain Index (13 items).[29] Mental well-being and vitality were measured with the Short-Form-36 scales mental well-being (five items) and vitality (four items).[26]

3.2.3 Analyses

Analyses were performed with the statistical package social sciences (SPSS version 7.5 for windows). We performed three regression analyses to determine the relative influence of each independent variable on the outcome variables strain, mental well-being and vitality.
Independent variables that correlated significantly (Pearson correlation, alpha=.10) with any of the outcome measures were included in the regression model. Intercorrelations were calculated for all these variables. If two variables were found to be strongly correlated, one of them was included in the regression analysis or separate regression analyses were performed with either variable as a predictor. The final set of predictors was entered into a multiple regression analysis for each outcome variable separately. Predictors were entered stepwise: first the patient and caregiver characteristics, using the ENTER method, and then all the resource and coping variables, using the FORWARD method.[30]

3.3 Results

Physical, emotional, cognitive and behavioral consequences from stroke as perceived in the patient were moderate to severe according to the SIP68 (percentile score 80-90).
Stroke had occurred 3.5 years ago on average (S.D.=3.81). The majority of the 212 caregivers interviewed were women, mostly patients' spouses. Their mean age was 64 years (S.D.=10.14), their socio-economic situation was middle class, and their physical and mental well-being was moderate (table 1).
Exploratory factor analysis based on the eigenvalues and explained variance showed that the instrument 'confidence in own knowledge' consisted of two factors: perceptions of the disease, resources and patient care (alpha=.94), and perceptions of self efficacy (alpha=.86). The two factors together explained 49.5% of the total variance. From this point the first factor will be called confidence in knowledge about patient care, and the second factor confidence in knowledge about self-efficacy.
For the measuring instrument 'assertiveness' another exploratory factor analysis was executed that yielded two factors. In view of the content of the items, we decided to use the questionnaire as a whole. Items with a low commonality were removed, leaving 11 items (alpha=.81). The explained variance of the questionnaire was 47.2%.
In table 2 the calculation of the correlations between the independent variables and the three outcome measures (strain, mental wellbeing, and vitality) are shown. The following 13 independent variables correlated significantly with at least one outcome measure (alpha=.10): 1) caregiver's and 2) patient's gender, 3) caregiver's age and 4) patient's age, 5) caregiver's physical health, 6) consequences from stroke as measured by the SIP-68, 7) emotional, 8) cognitive and 9) behavioral consequences of stroke as measured by Schure's instrument, 10) knowledge about stroke, resources and patient care, 11) perception of self efficacy, 12) the coping strategies confronting and seeking social support, and 13) satisfaction with social support.

Table 1: Initial caregiver characteristics

Initial caregiver characteristics	Controls (n=42)	Group program (n=110)	Home visits (n=60)	Max.Range
Caregiver characteristics				
Gender caregiver (% female)	71.4	74.5	71.7	
Mean age caregiver**	60.8	66.4	63.2	
Income*:				
% low (< € 1200)	45.0	65.0	58.9	
% high (> € 1200)	55.0	35.0	41.2	
Mean socio-economic status	44.1	46.4	45.5	0-100
Mean physical health**	73.1	64.8	74.1	0-100
Patient characteristics				
Gender patient (% male)	71.4	74.5	71.7	
Time of stroke:				
% < 3 years	51.2	40.9	46.7	
% > 3 years	48.8	59.0	53.3	
Sickness Impact Profile (SIP68)	26.1	26.5	28.0	0-68
Psychological consequences of stroke:				
Emotional consequences	12.2	12.3	12.1	6-24
Cognitive consequences	12.8	13.4	12.3	6-24
Behavioral consequences	9.8	10.1	10.2	5-20
Primary effect measures				
Confidence knowledge patient care**	68.1	62.2	66.3	23-115
Confidence knowledge self efficacy	19.4	18.0	18.4	7-35
Short version UCL: confronting	13.4	13.5	13.0	5-20
Short version UCL: seeking support	9.1	9.6	9.4	5-20
Secondary effect measures				
Caregiver Strain Index	25.9	26.3	25.6	13-39
SF-36: mental well-being	60.5	59.3	61.0	0-100
SF-36: vitality	55.4	52.1	56.1	0-100
Adjusted version SSL-I	10.6	10.1	10.0	5-20
Adjusted version SSL-D	8.8	8.3	8.6	5-10
Caregiver Assertiveness Index	34.6	34.0	34.5	11-44

* p<.10, **p<.05, tested with Chi Square and ANOVA

The calculated intercorrelations between these variables revealed high correlations between the variables caregiver's age and patient's age (R=.73), caregiver's and patient's gender (R= -.90), confidence in knowledge about patient care, and confidence in knowledge about self efficacy (R=.60), cognitive and emotional consequences (R=.58), behavioral and emotional consequences (R=.55), and cognitive and behavioral consequences (R=.54).
To prevent collinearity we decided not to include patient's age and gender in the regression model. Because we wanted to include emotional, cognitive and behavioral consequences, a total score for these consequences together was calculated. Confidence in knowledge about patient care, and self efficacy being two important variables in the model, we decided to execute two separate regression analyses, one for the outcome variable confidence in knowledge about patient care (analysis 1) and one for the outcome variable confidence in knowledge about self efficacy (analysis 2).
The multiple stepwise regression analysis (table 3) shows that several caregiver and patient characteristics contribute significantly to the three outcome measures.
Strain is influenced by four variables. Caregivers experienced more strain if they were younger (both analyses β=-.17, p<.05), the consequences of stroke were severe (both analyses β=.23, p<.001), the patient's cognitive, emotional and behavioral functioning had changed considerably due to stroke (both analyses β=.52, p<.001), and if caregivers were less satisfied with social support (analysis 1: β= -.21, p<.001, analysis 2: β= -.17, p<.001).
Mental well-being was lower in caregivers who were female (analysis 1: β= -.18, p<.01, analysis 2: β= -.18, p<.001), had poor physical health (both analyses β=.27, p<.001), looked after a patient with severe emotional, cognitive and behavioral consequences from stroke (both analyses β= -.37, p<.001), indicated having little confidence in knowledge about patient care (analysis 1: ns, analysis 2: β=.19, p<.001), made little use of the coping strategy confronting (analysis 1: β=.19, p<.001, analysis 2: β=.15, p<.01), and were less satisfied with the social support they received (analysis 1: β=.25, p<.001, analysis 2: β=.21, p<.001).
Vitality was lower in female caregivers (both analyses β= -.21, p<.001), in caregivers who were in poor physical health (both analyses β=.47, p<.001), looked after a patient with severe cognitive, emotional and behavioral consequences from stroke (both analyses β= -.26, p<.001), indicated having little confidence in knowledge about self efficacy (analysis1: ns, analysis 2: β=.22, p<.001), and expressed less satisfaction with the social support they received (analysis 1: β=.22, p<.001, analysis 2: β=.17, p<.01).
Concerning the relative influence of the independent variables on strain, mental well-being and vitality, we found caregivers to be most strongly affected by the variable cognitive, emotional and behavioral consequences of stroke.
Strain, mental well-being, and vitality were not influenced by the variables seeking social support, assertiveness, and the amount of social support that caregivers receive. From the correlation table (table 2) it can be concluded that duration of the caregiver role did not affect any of the outcome variables.

Table 2: Correlations between the independent and dependent variables

	Strain (n=193)	Mental wellbeing (n=193)	Vitality (n=192)
	R	R	R
Patient characteristics			
Gender patient	-.03	.26****	.27****
1= man			
2= woman			
Age patient	-.25****	.01	.03
SIP68 patient	.36****	-.21****	-.11
Schure:			
Cognitive consequences	.51****	-.28****	-.17**
Emotional consequences	.55****	-.42****	-.26****
Behavioral consequences	.51****	-.37****	-.34****
Caregiver characteristics			
Gender caregiver	-.00	-.23****	-.25****
1= man			
2= woman			
Age caregiver	-.20****	-.00	-.03
SF-36:			
Physical health caregiver	-.07	.32****	.49****
SES caregiver	-.01	.07	.02
Resource variables			
Confidence knowledge patient care	-.04	.15*	.18*
Confidence knowledge self efficacy	-.35****	.41****	.43****
Assertiveness	-.03	.07	.01
Income caregiver	.02	.08	.05
Short SSL-I:			
Amount social support	.03	.04	.06
Short SSL-D:			
Satisfaction social support	-.42****	.43****	.39****
Use of active coping strategies			
Short UCL:			
Coping strategy confronting	.12*	.19**	.11
Short UCL:			
Coping strategy seeking social support	.13*	-.05	-.09
Duration caregiver role			
Time since stroke	-.02	.06	.06
0=< 3 years			
1=> 3 years			

*p<.10, **p<.05, ***p<.01, ****p<.001

Table 3: Results of the multiple stepwise regression analysis

Independent variable	Strain β		Mental wellbeing β		Vitality β	
	An. 1 (n=192)	An. 2 (n=193)	An. 1 (n=192)	An. 2 (n=193)	An. 1 (n=191)	An. 2 (n=192)
Patient characteristics						
SIP-68	.23***	.23***	-.11	-.11	-.04	-.04
Emotional, cognitive, behavioral consequences	.52***	.52***	-.37***	-.37***	-.26***	-.26***
Caregiver Characteristics						
Gender caregiver (1=male, 2=female)	-.01	-.02	-.18**	-.18***	-.21***	-.21***
Age caregiver	-.17**	-.17**	-.04	-.04	-.03	-.03
Physical functioning cg	-.05	-.05	.27***	.27***	.47***	.47***
Adjusted R^2	.43***	.43***	.29***	.29***	.35***	.36***
Resource variables						
Confidence knowledge patient care						
Confidence knowledge self efficacy		-.17***		.19***		.22***
Satisfaction with support	-21***	-.17***	.25***	.21***	.22***	.17**
Use active coping strategies						
Coping strategy confronting			.19***	.15**		
Coping strategy seek social support						
Adjusted R^2	.46***	.49***	.38***	.40**	.39***	.43**

*p<.05, **p<.01, ***p<.001

3.4 Conclusions and discussion

The regression analysis shows that patient and caregiver characteristics, resource variables, and the use of active coping strategies influence caregivers' strain, mental well-being, and vitality. Women, younger caregivers, caregivers who are not in good physical health, and caregivers taking care of a patient with severe emotional, cognitive, and behavioral consequences from stroke, experience the most negative consequences from their caregiver role. The variable cognitive, emotional, and behavioral changes in the patient has the strongest negative influence on the caregiver. High confidence in knowledge about self efficacy, high satisfaction with social support, and frequent use of the coping strategy confronting all have a positive influence on the caregiver. Duration of the caregiver role does not influence caregivers' strain, mental well-being, or vitality.

From these results we can conclude that it is younger female caregivers of patients with severe consequences from stroke who are at risk for burnout. We also found important indications regarding the organization of an intervention for caregivers of stroke patients. The results

suggest that an intervention should educate caregivers about self efficacy, stimulate them to use the coping strategy confronting, and teach them how to mobilize social support in a way that is satisfactory to them.

Our finding that consequences from stroke have a strong impact on the caregiver is supported by a study by Schure.[2] Several studies among dementia patients did not demonstrate a relationship between the consequences of the disease and caregiver strain. [8-10] However, stroke frequently causes physical, emotional, cognitive, communication as well as behavioral disabilities in the patient. Compared with other diseases stroke causes the highest care needs.[31]

Kosberg, Miller and Schure support our finding that female caregivers experience more strain than male caregivers.[2, 32, 33] Miller et al. found that female caregivers perform more personal care activities than do male caregivers.[33] Hooyman found that these personal care activities cause a stronger increase in the level of strain compared with other care activities.[34] Barusch and Spaid, Hochschild, and Wilson reported that women spend more hours in caregiving, provide more physical help with self-care, and place more emphasis on the quality of the relation with the patient.[35-37]

We found that younger caregivers experience more strain, a finding that is supported by other studies.[7, 38] This might be explained by younger caregivers often having other obligations (work, children) in addition to the care for a relative. Periard found that younger caregivers perceived that they had to change their lifestyle more than did older caregivers.[38]

The finding that caregivers in good physical health experience less strain from caregiving is partly explained by Gold's study. Gold found that caregivers in better health were more likely to experience positive aspects of caregiving.[39]

The resource variables knowledge and social support were also found to influence caregivers' well-being. Regarding knowledge, the results of our study appear to demonstrate that confidence in knowledge about self-efficacy is more important than confidence in knowledge about patient care. If caregivers know how to make time for themselves, their hobbies, and their social life, know where to ask for support et cetera, they experience less strain. Apparently, it is not so much looking after the patient that causes the strain, but the fact that caregivers are unable to find time for themselves. The importance of performing activities for oneself is shown by the results of Nieboer's study.[40] Several other studies support our finding that satisfaction with social support has a positive influence on caregivers' well-being.[5, 41]

The importance of the use of active coping strategies (such as confronting) in relation with mental well-being, is supported by Matson. He found that the active strategy 'tactical coping' had a positive effect on strain and depression in caregivers of stroke patients, whereas the passive coping strategy 'non-confronting' had a negative effect.[18]

Duration of the caregiver role did not have any effect on caregivers' strain, well-being or vitality. From our study it can be concluded that people who had recently become caregivers experienced similar levels of strain to those who had been looking after a relative for a longer time.

Weaknesses of this study concern the cross-sectional design and the lack of a non-caregiver control group. In several cross sectional studies, like in our study, being a female caregiver is associated with strain and often depressive symptomatology. However, a longitudinal study under caregivers of Alzheimer patients found that female caregivers were more depressed at intake but male caregivers became more depressed over time.[42] Using a control group with non-caregivers would reveal if our findings are unique for caregivers.

Another weakness concerns the representativeness of our group of caregivers. The comparison of the group of caregivers included in our study with groups of caregivers of stroke patients in other studies and caregivers of stroke patients in the Netherlands revealed some differences. Other studies also reported the majority (72% to 78%) of caregivers to be female spouses.[43-45] In the Netherlands the majority of stroke patients are aged between 65-85 years, and their spouses are probably also in this age category. The caregivers in our study had a mean age of 64 years, which is somewhat lower. In the Netherlands the majority of the stroke patients have a low socio-economic status.[46-48] Caregivers in our study had a moderate socio-economic status. Apparently, it is difficult to include very old caregivers and caregivers with low socio-economic status in scientific studies. Because caregivers with low socio-economic status have fewer resources than those with higher socio-economic status, it would appear plausible that these caregivers show higher levels of strain than the group of caregivers described in this study.

This study demonstrates that severe cognitive, behavioral, and emotional changes in the patient constitute the most important risk factor for caregiver burnout. Furthermore, women, younger caregivers and caregivers in poor physical health form a risk group. To prevent burnout, support programs should be targeted at these caregiver groups in particular.

The results of our study suggest the following recommendations regarding the organization of support programs for caregivers of stroke patients. Support programs should include education about self efficacy, stimulation of the use of the coping strategy confronting, and training in mobilizing social support in a way that is satisfactory to caregivers. Furthermore, support programs should be offered both to caregivers who recently started to take care of a patient and to caregivers who have been taking care of a patient for a longer time.

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